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# Communication of the diagnosis of HIV infection

## - The experiences and preferences of patients -

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## Abbreviations

AIDS - *"Acquired Immunodeficiency Syndrome"*

IV - *"Intravenous"*

HIV -"*Human Immunodeficiency Virus"*

SD - "*Standard Deviation"*

# Abstract

**Objective**
The aim of this study is to inspect how patients receive the diagnosis of HIV infection, to identify their preferences in this situation and to find out if these preferences were met when they received their diagnosis. The influence of socio-demographic and clinical factors on patients' experiences and on their preferences was also examined.

**Methods**
Eighty patients with HIV infection from the Infectious Diseases Clinic in a central hospital in a major city in Portugal responded to a self-report questionnaire. Designed for this study, this questionnaire included items from the literature on communicating bad news organized to collect information about patients' experiences when notified of their first positive HIV test result and about their preferences regarding aspects of this specific moment. Data were analyzed with *t*-test and regression analyses in PASW 20.

**Results**
Regarding patients' experiences, most of the items in the questionnaire happened when the diagnosis of HIV infection was transmitted. The most and the least reported aspects both belong to the category "Setting". In patients' preferences regarding the communication of the diagnosis, more than half of the items were highly valued. These items were distributed equally by the four categories. However, there was a tendency for disagreement between patients' experiences and their preferences regarding the communication of the diagnosis in some aspects, especially associated with the categories, "What and how much information was provided" and "Emotional Support". The nationality and the context where the diagnosis was communicated influence patients' preferences regarding the communication of the diagnosis of HIV infection. The socio-demographic and clinical variables had no influence in the experiences of patients in this situation.

**Conclusion**
The transmission of the diagnosis of HIV infection seems to be in line with the existing guidelines' recommendations. The four categories related to patients' preferences for communication in cancer also seem to be applicable to HIV patients.
The preferences of patients with HIV infection need to be taken into account when training staff in the notification of this condition, as communication can be adjusted if certain patterns of preferences are recognized.
It is important to approach each patient in a individualized way, to understand what are the real needs of each one of them.

**Keywords:** bad news; communication; HIV infection; patient's preferences

# Resumo

**Objetivos**
Este estudo pretende verificar como os doentes receberam o diagnóstico de infeção VIH, quais as suas preferências nesta situação e descobrir se essas preferências correspondem à forma como receberam este diagnóstico. Outro objetivo deste estudo foi analisar a influência das variáveis sociodemográficas e clínicas sobre as experiências e suas preferências na comunicação do diagnóstico de infeção por VIH.

**Métodos**
Oitenta doentes (com infeção VIH) foram consecutivamente selecionados no Serviço de Doenças Infeciosas, num hospital central de uma grande cidade em Portugal, e responderam a um questionário. Elaborado para este estudo, o questionário teve como objetivo recolher informações sobre as experiências dos pacientes quando foram notificados, pela primeira vez, do diagnóstico de infeção do VIH e sobre as preferências relativamente a este momento específico. Os dados foram analisados com testes paramétricos no PASW-20 utilizado amostra independente *t*-test e análises de regressão (Regressão Logística e Regressão Linear Múltipla).

**Resultados**
De acordo com a opinião dos doentes, a maioria dos itens do questionário foram experienciados por mais de metade da amostra. Tanto os aspetos mais valorizados como os menos valorizados pertencem à categoria "Contexto terapêutico".
Relativamente às preferências dos doentes na comunicação do diagnóstico, mais de metade dos itens foram altamente valorizados, tendo sido distribuídos equitativamente pelas quarto categorias.
No entanto, em alguns casos houve discordância em aspetos associados às categorias: "O quê e quanta informação foi disponibilizada" e "Suporte emocional".
A nacionalidade e o local onde foi transmitido o diagnóstico influenciaram as preferências dos doentes na comunicação do diagnóstico de infeção por VIH. Contudo, as variáveis sociodemográficas e clínicas não influenciaram as experiências dos doentes nesta situação.

**Conclusões**
A comunicação do diagnóstico de infeção por VIH demonstrou concordância com as recomendações das *guidelines* existentes. De acordo com os resultados obtidos neste estudo, as quatro categorias, sugeridas por Fujimori, relacionadas com as preferências dos doentes com cancro, também podem ser aplicáveis aos doentes com infeção VIH.
As preferências dos doentes na comunicação do diagnóstico de infeção por VIH devem ser tidas em conta para auxiliar os técnicos de saúde que lidam com esta problemática.
É importante a aproximação de cada doente para conseguirmos entender quais são as suas verdadeiras necessidades no contexto da comunicação do diagnóstico de infeção por VIH.

**Palavras-chaves:** bad news; communication; HIV infection; patient's preferences; experiences in diagnosis HIV infection

# Index

# 1. Introduction

HIV infection is a slow, progressive immunological disorder. As there is neither a cure nor a vaccine for this problem, morbidity and mortality resulting from HIV infection will continue to challenge health care providers, including those who counsel patients with this problem[1].

HIV infection is a medical problem that has focused attention on communication with patients, particularly on the moment of transmission of the diagnosis, as it may represents a bad news, depending on patients' individual factors as well as on external circumstances, including the setting in which it is given[2]. There are many definitions of bad news. According to Buckman (1984)[3], bad news in medical context is defined as "any information likely to alter drastically a patient's view of his or her future". The way it is communicated may not alter the fact that the information is still bad news, but it may determine, or at least influence, how patients subsequently cope with, and adapt to their changing circumstances[1]. How the test result was communicated has been related to patient dissatisfaction and distress[4] and suggested to be an important contributor of suicidal behavior[4].

Surveys in general practice and hospitals have uncovered a link between the doctors' communication skills and patients' satisfaction, treatment compliance and outcomes in HIV care[4,5]. Yet, conveying bad news is a stressful task to many doctors who, in the absence of effective training, may adopt inappropriate ways of delivering this type of news and of coping with possible patients' emotional reactions[6]. The task of breaking bad news can be improved through the understanding of the process involved, and some authors suggest approaching it as a step-wise procedure with, application of principles of communication and counseling[7]. Guidelines for the communication of bad news have been created for the purpose of improving this difficult task. One of the best

known guidelines is the "six-step protocol of SPIKES", developed by Buckman (1992)[8]. This protocol incorporates the following steps: 1) Setting– arrange for some privacy, involve significant others, sit down, make a connection with the patient, manage time constraints and interruptions; 2) Perception – assess patients' perception, ask questions to discover what they already know about the medical situation; 3) Invitation – discover to what level of detail patients want to be informed; 4) Knowledge – give knowledge and information in a comprehensive way, using easy vocabulary and avoiding medical jargon or abbreviations to the patient; 5) Emotions – address the patients' emotions with empathic responses, allowing them to express their outbursts of emotions; 6) Strategy – provide all treatment plans available, summarize the discussions with the key points, set aside time and patience for patients to raise their questions and schedule for future appointments.

Bad news in medical contexts has traditionally been associated with terminal illness, imminent or actual death and cancer diagnosis. Thus, breaking bad news is a common topic in Oncology, an area in which a large number of studies have already been conduced, some of them focusing on patients' preferences regarding the communication of bad news and associated factors[9]. There is little research literature about the experience of receiving an HIV infection diagnosis from the perspective of these patients'[10] and even less regarding their preferences about to receive this diagnosis. The majority studies related to HIV has focused on attitudes toward testing, reasons of testing, and behavioral outcomes following the test counseling session[10]. One study by Pergami et al. (1994)[4] aimed at obtaining information about patients' experiences of the manner in which a diagnosis of HIV infection was notified to them, and to identify factors associated with patients' satisfaction with patient-staff communication. This study reported that only about one-third of the patients' were definitely satisfied with

the way they were told the diagnosis and that satisfaction was associated with perceived reassurance and sympathy by the doctor, and with the quality of the information given[4]. Focusing only on the actual experience of the transmition of the diagnosis of HIV infection, this study did not take into account how patients wanted that moment to be. It reports patients' satisfaction, but not their preferences. Another study described individual experiences of receiving a positive HIV test by qualitative analysis of transcribed interviews of 50 participants[10].

To our knowledge, there are no quantitative studies in the Portuguese population about patients' preferences on the way the diagnosis should be given.

Since patients' lives are directly affected by the communication of unfavorable news, it is important to study the moment when patients receive their HIV diagnosis and how they would like to be informed of their condition. Increased knowledge in this domain can contribute to the formulation of guidelines which will help health professionals deliver bad news to HIV patients, taking into account their needs and preferences. The aims of this study are: 1) to inspect how patients have received the diagnosis of HIV infection, 2) to identify their preferences in this situation, and 3) to find out whether these preferences were met when they received their diagnosis and on what aspects. The influence of socio-demographic and clinical factors on patients' experiences receiving the diagnosis and on their preferences is also examined.

# 2. Methods

## *2.1 Procedures*

This study was conducted between March and June of 2013 with outpatients of a central hospital in a major city in Portugal who received an HIV-positive test result in the past and who are presently attending follow-up medical appointments in the Infectious Diseases Clinic. The study consisted of patients responding to a confidential and anonymous questionnaire and was approved by the hospital ethics committee. Patients were consecutively selected in the waiting area before their doctors' appointments at different points in time. They were given a brief description of the study and were asked to participate upon confirmation of age and education level. Subjects older than 18 years of age and a minimum educational level of 4 years were included. The study began immediately with those who gave their informed consent.

## *2.2 Participants*

Eighty-five patients were asked to participate in the study. However, five patients declined because they did not have enough time, or were not interested in participating in research. The final sample was composed of 80 patients (appendix, Table 1) presents the sample characteristics. Most participants were Portuguese (n=75, or 93.8% of the sample), 29 (36.3%) were female and 51 (63.8%) were male. HIV infection is more common among men than among women. In Portugal there are 31255 reported cases of men with HIV infection (73,4%) and 11312 reported cases of woman with this infection (26,6%), plus 13 cases with unknown gender[11]. A similar gender proportion is found among the HIV population followed in the hospital where this study took place (1562 men corresponding to 73.6%, of the total, and 560 woman, or 26.4%).

Thus, men are somewhat underrepresented and woman are overrepresented in this sample. The sample's mean age was 42.3 years old (SD=8.27) and mean education level was 8.35 years (SD=4.01). Mean time since the diagnosis was 91.9 months (SD=77.9). The disease was sexually transmitted in 63 of the participants (78.8%), and transmitted by blood contamination in 17 participants (21.3%) who were all intravenous drug users.

## *2.3 Instruments*

A self-report questionnaire was used to collect information about: 1) patients' experiences when they were notified of their first positive HIV test result, and 2) about their preferences regarding aspects of this specific moment (appendix). Designed for this study, the questionnaire was based on a review of the literature concerning patients' preferences on the communication of bad news. Most items considered relevant for the purposes of this study were found in research in cancer[11,12]. The remaining items were taken from studies in other areas such as pregnancy diagnostic abnormalities and HIV infection[8,13,4,12]. The word "cancer" was replaced by "HIV" in one item. As proposed by Fujimori et al. (2009)[11] in a large review of preferences of cancer patients regarding communication of bad news, these items can be grouped in four categories, in which they were included: setting, with 12 items (numbers 11, 12, 18, 19, 20, 25, 26, 27, 29, 30, 31 and 37), manner of communicating the diagnosis/bad news, with nine items (numbers 1, 2, 3, 4, 5, 8, 14, 17 and 28), what and how much information was provided, with eight items (items 6, 7, 9, 10, 15, 16, 35 and 36) and emotional support, with nine items (numbers 13, 21, 22, 23, 24, 32, 33, 34 and 38) (appendix, Table 2). These items were mixed in the written questionnaire delivered to the participants for validity purposes.

The questionnaire was divided in 2 sections:

1) In the first part of the questionnaire patients were asked to mark each 38 of items as "yes" or "no" according to whether or not they applied to their own experience when they received the diagnosis of HIV infection.
2) In the second part, for each of the same 38 previous items, according to the way they would like to have received the news about the diagnosis of HIV infection.

   Patients rated their preferences on a five-point Likert scale, where "1" represents "completely unimportant" and "5" "extremely important".

   For this second part, participants were asked to go back to the moment when they were first told they had HIV infection and to respond to the questions as they would like to have been told.

Finally respondents answered questions on socio-demographic and clinical information including gender, age, nationality, marital status, education, occupation, monthly income, sex orientation, time of diagnosis, way of HIV transmission and the location where the diagnosis was communicated (emergency room, primary care center, outpatient care, inpatient care, by letter or others).

## *2.4 Statistical Analysis*

Data were analyzed in PASW 20. In addition to descriptive statistics independent sample *t*-tests were performed to check whether or not patients' experiences at the time of the diagnosis (yes, it did happens; no, did not happen) matched their preferences for receiving the diagnosis (measured though patients' means on the 5-point Likert scale) for each of the 38 items. Regression analyses were additionally used to inspect the contribution of socio-demographic and clinical variables to patients' experiences and preferences (gender, age, nationality, marital status,

education, occupation, sexual orientation, monthly income, time since the diagnosis of HIV, form of disease transmition and where the communication of the diagnosis took place). Binary Logistic Regression using the backward likelihood ratio (LR) method was employed to explore the influence of socio-demographic and clinical variables on patients' experiences for each of the 38 items.

This method is less likely to produce type II errors than the stepwise forward method[14]. Multiple Linear Regression using the hierarchical method was employed to inspect the influence of socio-demographic and clinical variables on patients' preferences for each of the 38 items. Sex, age and education were included in the first block, as past research suggests that these variables affect patients' preferences[9]. Bonferroni correction was applied ($\alpha$=0.001).

# 3. Results

## *3.1Patients' experiences regarding the communication of the diagnosis of HIV infection*

Seventy-four patients returned the first part of the questionnaire (92.5% of the sample). The other six patients did not complete this part of the questionnaire because they received the diagnosis of HIV infection by letter, not in an appointment with a physician. Thus, analyses of patients' experiences at the moment of the diagnosis are carried out for n=74. The results on the aspects patients reported having happened when they received the diagnosis are displayed in Table 3 (listed in descending order of number of marked items) (appendix).

Overall, patients reported that most items included in the questionnaire happened when they received their diagnosis. More than half of the sample gave a positive response ("yes") to 26 items (68.4% of the total number of items). The items with the highest number of positive responses ("yes" from more than 80.0% of the sample) are distributed by the four categories. The item almost all respondents marked with "yes" was 36. "Used the word "HIV/AIDS" part of "What and how much information was provided" (69 respondents, or 93.2% of the sample). Next, also receiving a positive response from almost all respondents was item 27. "Was sitting, and I was too", part of "Setting" (68 respondents, or 91.9% of the sample). All other highly scoring items received "yes" from less than 90% of the sample. Most belong to "Setting": 26. "Gave the information in person (rather than over the phone)" (66 respondents, or 89.2% of the sample), 12. "Gave me information without interruptions" (64 respondents, or 87.7% of the sample), 25. "Told me in a private setting" (64 respondents, or 86.5% of the sample), 18. "The physician alone gave me the information" (62 respondents, or 83.8% of the sample) and 11. "Greeted me before starting the appointment" (60 respondents, or 81.1%

of the sample). An item also receiving many positive responses was 3. “Gave me information in a clear and understandable way”, part of “Manner of communicating the diagnosis” (65 respondents, or 87.8% of the patients). “Emotional support” received “yes” from many respondents for item 34. “Scheduled a follow-up appointment” (62 respondents, or 83.8% of the sample) and for item 21. “Seemed to be friendly/ empathic” (60 respondents, or 82.2% of the sample). All other items present percentages of positive answers below 80%, starting with 10. “Discussed the disease’s implications in my everyday life” (57 respondents, or 77.0% of the sample), again part of “What and how much information was provided”.

Thus, of the 10 items receiving the highest positive scores from this sample of HIV patients (between 81.0% and 93.5% marking “yes, it did happen”) most (six) belong to the category **“**Setting” (corresponding to half of the 12 items that form this category). Two belong to “Emotional support” (less than one third of the nine items in this category), one item is part of “Manner of communicating the diagnosis” (containing also nine items), and one item is part of “What and how much information was provided” (which includes a total of eight items).

On the other hand, eight items received relatively few positive responses (“yes” responses from less than 40.0% of the sample). The two items that, according to respondents, happened the least had to do with patients having company at the time of the diagnosis: 30. “I was with my spouse/ partner” (only 15 respondents marked “yes”, corresponding to 20.3% of the sample) and 31. “I was with a family member/ friend” (17 respondents, or 23.3% of the sample, marked “yes”). Next, few patients gave a positive response also to item 19. “Gave me the information with other health professionals” (21 respondents, or 28.4% of the sample). Related with these aspects, two other items received few positive responses (although more positive responses than

the previous three aspects): items 37. “Asked if I would like a supportive person to be present, before giving the news” and 20. “The senior doctor gave me the information after discussing it with the team”, with 28 “yes” responses each (or 37.8% of the sample for each item). These five items are part of “Setting”. Few respondents said “yes” to item 38. “Asked if I needed help getting home” (21 respondents, corresponding to 28.4% of the sample), which is part of “Emotional support”. In “Manner of communicating the diagnosis”, 23 respondents marked “yes” in 14. “Gave me extra written information (31.1% of the sample). In the category “What and how much information was provided” 27 respondents (36.5% of the sample) marked “yes” to item 6. “Gave me the information with the help of exams/tests/drawings”.

In sum, “Setting” is the most represented category also among the items that happened the least during the delivery of the diagnosis. Of the eight items receiving the smallest number of positive responses, five are part of “Setting” and correspond to almost half of the 12 items in this category. The other categories, “Manner of communicating the diagnosis” and “Emotional support”, had one item (out of 9) each, and “What and how much information was provided” had one in a total of eight items in this category.

Logistic Multiple Regression shows that socio-demographic and clinical variables do not significantly influence patients’ experiences at the time of the diagnosis of HIV infection for any of the aspects considered.

## 3.2 *Patients' preferences regarding the communication of the diagnosis of HIV infection*

All participants responded to this second part of the questionnaire (n=80). The sample mean for the all the items was 4.35 (SD=0.66), indicating that patients' preferences for these aspects are generally high. More than half of the items were highly valued (mean>4.60 for 21 or 55.3% of the items). Table 4 (appendix) list all aspects in descending order of patients' mean preference.

The 11 items with the highest ratings (mean>4.80) were evenly distributed by the four categories. The item receiving almost the highest possible score was 3. "I would like the physician to have given me information in a clear and understandable way" (mean=4.95; SD=0.27). This item was also classified in the top positions of the experiences patients reported having when they received the diagnosis, which suggests that what they prefer actually happened at the time of the diagnosis for this aspect. All others items present mean values below 4.90. The next item with a high mean preferences value was 28. "I would like the physician to have asked me if I had any doubts or questions" (mean=4.89; SD=4.23), though the SD indicates variation in the sample's preferences for this aspect. These two items are part of the "Manner of communicating the diagnosis". An item with the same mean value as the previous one and a much smaller SD was 10. "I would like the physician to have discussed the disease's implications in my everyday life" (mean=4.89; SD=0.45). With a mean value very close to this, item 16. "I would like the physician to have given me information about the disease's progression" was also highly valued (mean=4.88; SD=0.46). Both these items are part of the category "What and how much information was provided". Item 25. "I would like the physician to have told me in a private setting" had a mean preference value similar to the previous aspects (mean=4.89; SD=0.55). This and the

following most preferred item, 26. “I would like the physician to have given the information in person (rather than over the phone)” (mean=4.85: SD=0.68) belong to the category “Setting” and represent 2/12 of the items in this category. Both these items were also classified in the top positions of the experiences patients reported having at the time of the diagnosis. With the same mean value as the previous item, 34. “I would like the physician to have scheduled a follow-up appointment” (mean=4.85; SD=0.42), which was also classified in the top positions of patients’ experiences at the time of the diagnosis, and with close mean values, 23. “I would like the physician to have given me support for my distress/fears” (mean=4.83; SD=0.52) and 13. “I would like the physician to have encouraged me to ask questions” (mean=4.81; SD=0.62) are part of “Emotional support” and represent 3/9 of the items in this category. Next, item 17. “I would like the physician had checked to see if I understood the information” (mean=4.84; SD=0.49) is part of the category “Manner of communicating the diagnosis”, which contains 3/9 of its items in this group of most valued preferences. Lastly, item 15. “I would like the physician to have given me information about the treatment” (mean=4.81; SD=0.55) is included in category “What and how much information was provided” representing, together with others already described, 3/8 of the items in the category.

In sum, five of the 11 items patients prefer the most are reported as having happened at the time of the diagnosis also by the greatest number of participants (including 10.“ I would like the physician to have discussed the disease’s implications in my everyday life”). But six items in the group of the most marked 10 aspects happening at the time of the diagnosis are not included in the 11 items patients prefer the most (36. “I would like the physician to have used term HIV/AIDS” (in category “What and how much information was provided”), 27. “I would like the physician to

have been sitting, and me too", 12. "I would like the physician to have given me information without interruptions", 18. "I would like the physician alone to have given me the information", 11. "I would like the physician to have greeted me before starting the appointment" (in category "Setting") and 21. "I would like the physician to have seemed to be friendly/empathic" (in "Emotional support" category).

The seven items with the lowest preference ratings (mean<4.00) were distributed by three categories. Two of the lowest scoring items had to do with having company at the time of the diagnosis: 31. "I would have liked to be with a family member/ friend" (mean= 2.65; SD=1.79) and 30. "I would have liked to be with my spouse/partner" (mean=2.91; SD=1.79). Two other items whit low ratings had to do with the involvement of the team of health professionals in the diagnosis situation: 19. "I would like the physician to have gaved me the information with other health professionals" (mean=2.86; SD=1.80) and 20. "I would like the senior doctor to have given me the information after discussing it with the team" (mean=2.86; SD=1.69). These four items are part of "Setting" and were also classified in the lowest positions of patients' experiences at the time of the diagnosis. The next item with a low mean preferences value was 14. "I would like the physician to have given me extra written information" (mean=2.88; SD=1.75), part of "Manner of communicating the diagnosis" and also marked by few patients as happening at the time of the diagnosis. Another two aspects that belongs to the seven lowest valued items are 6. "I would like the physician to have given me the information with the help of exams/tests/drawings" (mean=3.35; SD=1.70) and 7. "I would like the physician to have immediately transmitted all diagnosis details" (mean=3.64; SD=1.68), both part of "What and how much information was provided". The former also appeared under the items that received fewer marks for having happened at the time of the diagnosis.

In sum, “Setting” contains four of the seven least valued items (4/out of the 12 in this category) and “What and how much information was provided” contains two of these items (2/8 of the category) and “Manner of communicating the diagnosis” contains one (out of nine in this category). No item from “Emotional support” appears in the seven lowest valued items. Almost all of these least preferred aspects (six) appear also among the eight aspects that least happened at the time of the diagnosis. The two items few patients marked as having happened at the time of the diagnosis that are not included in the group of the seven least preferred aspects were 37. “I would like the physician to have asked would like a person present” and 38. “I would like the physician to have asked if I needed help getting home”.

Multiple Linear Regression shows that, overall, socio-demographic and clinical variables contribute little or moderately to explaining the variation in patients’ preferences for the communication of the diagnosis of HIV infection (median $R^2$= 0.27 [0.17-0.62] across the 38 items considered). After Bonferroni correction, there were five statistically significant associations between socio-demographic or clinical characteristics and patients’ preferences. The location in which patients received the diagnosis influences their preferences for the information received. Preference for receiving information without interruptions increases significantly by 1.598 in patients who received the diagnosis in outpatient care compared to those who received it by letter (*p*=0.000). Preference for receiving information about the treatment increases by 0.878 also in patients who received the diagnosis in outpatient care compared to those who received it by letter (p=0.001). Preference for receiving information with the additional support of exams/tests/drawings increases significantly by 2.631 in the context of outpatient care compared to the context of emergency situations (*p* = 0.000). Finally, the location in which patients received the diagnosis influences their

preferences also for the content of the information. Preference for discussing the disease's implications in daily life increases by 0.507 in the context of outpatient care compared to the context of the emergency room ($p$=0.000). This preference for discussing the disease's implications in daily life is also influenced by the patient's nationality. Preference for this aspect increases by 0.819 in Portuguese patients compared to patients of other nationalities ($p$=0.000).

The first item is part of "Setting". All other items are part of "What and how much information was provided". No statistically significant association between socio-demographic or clinical characteristics and patients' preferences was found for the categories of "Manner of communicating the diagnosis" and "Emotional support".

## 3.3*Comparison between patients' experiences and preferences regarding the communication of the diagnosis of HIV infection*

Results show agreement between patients' preferences and their experiences regarding the communication of the diagnosis in two of the 38 items, both part of the "Setting" category: 19. "Gave me the information with other health professionals" and 30. "I was with my spouse/ partner" (Table 5 – Appendix). Patients reporting that these two aspects happened at the time of the diagnosis present higher mean preferences for each of them (mean=4.48; SD=0.98 and mean=4.47; SD= 1.13, respectively) than patients reporting that these two aspects did not happen at the time of the diagnosis (mean=2.25; SD=1.65 and mean=2.49; SD= 1.74, respectively). These differences are statistically significant ($t(61)=7.153$, $p=0.000$ and $t(33)=5.366$, $p=0.000$, respectively). In the previous section, these two items were included in the group of the least valued aspects (Table 4), displaying means well below the sample mean for preferences (sample mean=4.35; SD=0.66). After dividing the sample in the two groups, results indicate that these low values reflect the low valuation by the patients who reported not having had the experience at the moment of the communication of the diagnosis even though for the other group of patients these two items also display means below this group's mean of preferences (group mean=4.60; SD=0.43).

There is a tendency for a match between patients' preferences and experiences regarding the communication of the diagnosis in another four items, included in three categories: "Setting", "Manner of communicating the diagnosis" and "What and how much information was provided". In the "Setting" category, patients who reported that 18. "The physician alone gave me the information" present higher mean preferences for this aspect (mean=4.73; SD=0.83) than patients who reported not having had this experience at the time of the diagnosis (mean=3.83; SD=1.27), $t(13)=2.343$, $p=0.036$.

Patients who said that 20. “The senior doctor gave me the information after discussing it with the team” present higher mean preferences for this aspect (mean=4.04; SD=1.45) than patients who said they did not have this experience at the time of the diagnosis (mean=3.13; SD=1.73), $t(65)=2.398$, $p=0.019$. In the category “Manner of communicating the diagnosis”, patients who reported that 8. “Gave me customized/personalized information” display higher mean preferences for this aspect (mean=4.78; SD=0.54) than patients who said they did not have this experience at the time of the diagnosis (mean=3.91; SD=1.38), $t(24)=32{,}887$, $p=0.008$. In the category “What and how much information was provided”, patients who reported that 6. “Gave me the information with the help of exams/tests/drawings” display higher mean preferences for this aspect (mean=4.00; SD=1.66) than patients who said they did not have this experience at the time of the diagnosis (mean=2.98; SD=1.66), $t(72)=2.531$, $p=0.014$. Two of these aspects present mean values above the sample mean and also above the group mean for the group who reported having had the experiences at the time of the diagnosis: 8. “Gave me customized/personalized information” and 18. “The physician alone gave me the information”. The other two items are less valued, presenting mean values below the sample and the group means. The mean values of each of these four aspects are all below the sample and the group means for the patients reporting not having had these experiences at the time of the diagnosis. However, these tendencies loose statistical significance after the application of Bonferroni correction ($\alpha = 0.001$).

Results further show tendencies for disagreements between patients’ reported experiences and preferences regarding the communication of the diagnosis in three items, all part of the category, “What and how much information was provided”. Patients who reported that the physician 10. “Discussed the disease’s implications in my

everyday life", 15. "Gave me information about the treatment" and 36. "Used the word "HIV/AIDS"", display lower mean preferences for these aspects (respectively, mean=4.86; SD=0.52, mean=4.79; SD=0.60 and mean=4.19; SD=1.33) than the patients who said they did not have these experiences at the time of the diagnosis (respectively, mean=5.00; SD=0.00, mean=5.00; SD=0.00 and mean=4.80; SD=0.45). The corresponding *t*-tests are: $t(56)=-2.056$, $p=0.044$; $t(52)=-2.518$, $p= 0.015$ and $t(11)=-2.386$, $p=0.037$. The mean values for these three aspects are very high among the group reporting they did not happen at the time of the diagnosis (two of them displaying the maximum possible value in the Likert scale, with little sample variation). Two are also high for the group reporting that they happened at the time of the diagnosis (the third presents a mean value below this group's mean: 36. "Used the word "HIV/AIDS""). However, again, these tendencies lose statistical significance after the application of Bonferroni correction.

For the remaining items, differences between means of preferences for the groups of patients who did and who did not have the respective experiences at the time of the diagnosis are statistically non-significant and start to approach zero. For eight of these items, this difference is very small ($-0.1<$mean difference$<0.1$). Even though both groups display high mean preference values for these items, one group had the experiences happening at the time of the diagnosis but the other group did not. The eight items are distributed by all the categories. However, half of them are part of "emotional support": Items 33. "Gave me hope" (mean=4.77; SD=0.70 for those who had the experience; mean=4.71; SD=0.96 for those who did not), 38. "Asked if I needed help getting home" (mean=4.29; SD=1.45 for those who had the experience; mean=4.25; SD=1.27 for those who did not), 23. "Gave me support for my distress/fears" (mean=4.89; SD=0.43 for those who had the experience; mean=4.87;

SD=0.58 for those who did not) and 22. “Showed concern for my distress/fears” (mean=4.78; SD=0.632 for those who had the experience; mean=4.81; SD=0.40 for those who did not). Two items pertain to the category “Setting” (12. Gave me information without interruptions” (mean=4.75; SD=0.82 for those who had the experience; mean= 4.78; SD=0.67 for those who did not) and 27. “Was sitting, and I was too” (mean=4.63; SD=0.86 for those who had the experience; mean=4.67; SD=0.82 for those who did not). One is part of "Manner of communicating the diagnosis" (3. “Gave me information in a clear and understandable way” (mean=4.95; SD=0.28 for those who had the experience; mean=5.00; SD=0.00 for those who did not)), and one belongs to "What and how much information was provided" (16. Gave me information about the disease progression” (mean=4.87; SD=0.50 for those who had the experience; mean= 4.96; SD=0.19 for those who did not)).

On the other hand, some aspects registered similarly low preference mean values in each group. For example, Items 7. “Immediately transmitted all diagnosis details” and 14. “Gave me extra written information”. However, they still happened in some cases.

# 4. Discussion

This study focuses on the experiences and on the preferences of a group of HIV patients concerning the communication of their HIV-infection diagnosis.

***Patients' experiences regarding the communication of the diagnosis of HIV infection***

Overall, patients reported that most of the items included in the questionnaire happened when they received their diagnosis. Most of the items patients marked as having happened at the time of the diagnosis pertain to "Setting". Generally, patients were greeted before receiving the diagnosis', the information was given to them in person and sitting down in a private space, without interruptions and only by the physician. Thus, creating an appropriate setting seems to be a special concern of those who transmit the diagnosis, since half of the items included in this category, "Setting", happened to most of the patients. These aspects have been suggested as important in the creation of an ideal environment for breaking bad news[12]. Interestingly, almost the other half of this category (five items) appears among the aspects marked as happening the least when the diagnosis was received. Three of these aspects are related to the patient having company at the time of the diagnosis (the presence of a spouse or of a family member/friend, and the physician asking if the patient would like a supportive person present, before giving the news) and seem to depend more on patients' than on physicians' attitudes (though more physicians asking whether the patient would like to have a supporting person present could help patients consider this possibility more positively). The other two least marked "Setting" items had to do with the involvement of a team of health care professionals in the communication of the diagnosis (given by a senior doctor after discussing it with the team and by a physician with other health professionals) and show consistency with many patients reporting that the physician

alone gave them the information (discussed above). In sum, the items in "Setting" represent the majority of aspects reported as happening the least and also as happening the most at the moment of the diagnosis. This category is practically exhausted between these two extreme positions.

Comparing to "Setting", few items pertaining to the other categories appear among the group of aspects reported as happening the most and the least at the time of the diagnosis. In "What and how much information was provided", "Manner of communicating the diagnosis" and "Emotional support", many physicians used the term HIV/AIDS, communicated with clear and intelligible language, were perceived as friendly and empathetic, and scheduled a follow up appointment. This is in line with guidelines' recommendation that physicians consciously choose words carefully, try to speak using simple, colloquial language, and avoid technical words[9,15]. On the other hand, in these same categories, giving extra written information, using the help of exams/tests/drawings to inform, and asking patients if they needed help getting home were reported as happening little at the time of the diagnosis. Most likely, this set of aspects does not reflect what may is current practice of Portuguese physicians and also in this situation were not implemented in the majority of the patients.

In the current study, socio-demographic and clinical variables do not influence patients' experiences in the communication the diagnosis of HIV infection. This may reflect that, regardless of the factors involved, the way the diagnosis was transmitted across this sample was similar. Or this could be also associated with Bonferroni correction that can be associated with an increase of Type II error, failing to identify differences that may exist. Nevertheless, there were similar results in Wensing (2002)[17] study that found that communication was not related to patient gender, education, age, functional health status or existence of chronic conditions.

***Patients' preferences regarding the communication of the diagnosis of HIV infection***

Concerning patients' preferences for the aspects presented in the questionnaire, in general, the majority of the items were also highly valued. All categories ("Setting", "What and how much information was provided", "Manner of communicating the diagnosis" and "Emotional support") are similarly represented among the most preferred items. This may suggest that the four categories Fujimori[9] indicates as related with patients' preferences for communication in cancer may also apply to patients with HIV infection. The item, "I would like the physician to have given me information in a clear and understandable way" reached almost the maximum possible value on the Likert scale. In the large review conducted by Fujimori[9] in cancer patients, most patients prefer that their physicians communicate bad news clearly and honestly, in a manner that facilitates each patient's full understanding[9.] Again, there seems to be agreement between the context of cancer and HIV infection for this aspect.

On the other hand, the four categories are unevenly represented in patients' least preferred aspects.

Four of the seven least preferred items belong to "Setting" and coincide with the aspects reported as also happening the least at the time of the diagnosis. Being accompanied by the spouse of by family members/friends and being informed of the diagnosis by a senior doctor after he or she discussed the information with the team, or by the physician with the help of a team of health professionals are part of the aspects that received the lowest preference values by patients. There is a wide variation in patients' preferences about having relatives present when receiving bad[9]. A Portuguese cancer study reported that most of the patients (65% of the sample) were with a family member when they received the diagnosis, and this was the way the majority of

participants desired it to be[16]. This is in contrast with Ishaque's[12] study showing that more than a half of the respondents were strongly opposed to the idea of having doctors breaking bad news in front of their families and preferred their doctors to address their emotional needs in this situation[9.] In fact, in our study, none of the items in the category "emotional support" is part of the group of aspects patients prefer the least. Seven out of nine items in this category present high ratings, considerably higher than the sample mean. Only the two least preferred aspects under "Emotional support", 38. "I would like the physician to have asked if I needed help getting home" and 32. "I would like the physician to have cared for significant others who could help me deal with the news" display a lower mean than the sample. Other aspects which also had low preference ratings were receiving information with the help of exams/tests/drawings, receiving written information in addition to the verbal communication (both appearing also among the items that happened the least at the time of the diagnosis) and immediately being given detailed information about the diagnosis. Possibly, in the situation of receiving a diagnosis of HIV infection, patients prefer to remain focused on the essential aspects of the verbal communication without needing extra information that may be better processed at another time. The last mentioned aspect is the only aspect in this group of the least preferred items that is not part of the aspects that happened the least at the time of the diagnosis. All other least preferred items coincide with the items that actually least happened at the time of the diagnosis. This is an initial indication that physicians may adapt their communication strategies to their patients' and do not burden the patient with aspects that he or she does not value.

Although other studies reported that age, gender and education affect preferences for the communication of bad news[9,18,19,20]. In the present study, only two variables had impact in patients' preferences: one socio-demographic and other clinical.

The first variable is nationality, and renders the Portuguese patients more compliant to discussing disease's implication in everyday life, which may reflect cultural issues or language barrier. The second one is the place where patients received the diagnosis, particularly in the outpatient care as opposed to the other contexts, as the emergency room and remote communication, by letter. The emergency room may be seen by many as a stressful environment which determines special needs regarding the communication of bad news. It is possible that patients in such an emergent context intend to be informed in an objective and straightforward way. When it comes to being informed by letter of an HIV diagnosis, is understandable that the preference for detailed discussion of details about the treatment and receiving information without interruptions is decreased when compared with someone who personally receives information through a health care professional.

***Comparison between patients' experiences and preferences regarding the communication of the diagnosis of HIV infection***

Agreement between patients' preferences and reported experiences regarding the communication of the diagnosis occurred in two items, both part of "Setting" (19."Gave me the information with other health professionals" and 30. "I was with my spouse/partner"). For these two aspects, participants who did not have the respective experiences at the time of the diagnosis show a lower level of preference for each of them than participants who did have the experience. Both these aspects assume low values in the list of each group's preferences.

A tendency for agreement between patients' experiences and preferences regarding the communication of the diagnosis occurred in another four aspects ($p<0.05$), two of which also generally assume low values in patients' list of preferences: 6. "Gave

me the information with the help of exams/tests/drawings", 20. "The senior doctor gave me the information after discussing it with the team", 18. "The physician alone gave me the information" and 8. "Gave me customized/personalized information". Again, for these aspects, participants who did not have the respective experiences at the time of the diagnosis display lower preference levels than participants who reported having had the experiences. Additionally, there was a tendency for disagreement between patients' experiences and preferences regarding the communication of the diagnosis in three generally valued aspects (negative differences between the mean preferences of the groups; $p<0.05$): 10. "Discussed the disease's implications in my everyday life", 15. "Gave me information about the treatment" and 36. "Used the word "HIV/AIDS"". These three aspects were also highly valued (the first two reaching mean=5 on the 5-point Lickert scale) by patients who, however, reported they did not happen at the time of the diagnosis. Even though these tendencies are statistically non-significant after the application of Bonferroni's correction, they nevertheless underline the need for more attention to patients' necessities in the communication of the HIV diagnosis regarding these aspects.

Finally, several aspects registered no statistically significant differences between the mean preferences of the groups who either had or had not the experiences when notified of the diagnosis (the differences between these means are, for several aspects, close to zero; $p>0.05$). This may suggest that though most participants value each item similarly, some have had the experience at the time of the diagnosis and others have not. Two items for which patients in both groups show little preference are, 7. "Immediately transmitted all diagnosis details" (in the category "What and how much information was provided") and 14. "Gave me extra written information" (in "manner of communication the diagnosis"). Yet, these aspects still happened in some cases and may need special

attention in the communication of the diagnosis of HIV infection. On the other hand, eight items were highly valued by the two groups. While these aspects are distributed by all four categories, half of them are part of “Emotional support”: Items 33. “Gave me hope”, 38. “Asked if I needed help getting home”, 23. “Gave me support for my distress/fears” and 22. “Showed concern for my distress/fears”. The others are part of “Setting” (12. “Gave me information without interruptions” and 27. “Was sitting, and I was too”), "Manner of communicating the diagnosis" (3.” Gave me information in a clear and understandable way”) and "What and how much information was provided" (16. “Gave me information about the disease progression”). Additionally, three aspects for which the differences between the mean preferences of the groups have a negative sign again indicate that individuals who showed a higher level of preferences for the aspect did not have that experience at the time of the diagnosis: 26. “Gave the information in person (rather than over the phone)”, 21. “Seemed to be friendly/ empathic” and 1.”Asked what I knew about the disease before breaking bad news”

These results suggest that there is room for improving the communication of the diagnosis of HIV infection in general and with respect to aspects of emotional support in particular.

Some limitations of the current study should be noted. First, the small sample size limited some analyses. This study included 80 patients. Second, this was a convenience sampling drawn from a single location and raises questions about the external validity of the data. Therefore it cannot be representative of HIV infected patients in general. However, the sample included patients of both genders, from various age groups and with different lengths of time since they received the diagnosis that we believe that could be representative. A third important limitation is that the questionnaire was not

submitted to a validation process, as suggested by guidelines on this topic. However, from now on, it can be used in futures studies.

Another limitation is that the study is retrospective. Months or years have passed since the diagnosis of HIV infection was communicated. This means that some distortion and selective recall may have occurred when patients had to remember the moment when the bad news was given. Our study design is cross-sectional, where patients' preferences were evaluated on a single moment of time. It does not provide information about whether individual patients' preferences vary over time. It has been reported that patients' informational needs may change during the course of their illness and treatment and that patients may want more specific information earlier in their treatment[18,21]. Lastly, mood should be evaluated when studying ratings of preferences, as it may affect reporting of data[4]. A description of the subjects at this level, which was not done in this study, could be helpful for interpreting results.

**Future research** on this topic should include multicenter studies, preferably with a large number of patients and a prospective design. In this way, we could improve our knowledge about this matter and develop appropriate guidelines for the transmission of bad news to this specific population.

# 5. Conclusion

This study provides knowledge regarding experiences patients had in receiving the diagnosis of HIV infection and regarding patients' preferences in this situation.

Overall, transmission of the diagnosis seemed to be in line with the existing guidelines' recommendations. Creating an appropriate setting for communicating was a major concern of the physicians who transmitted the diagnosis. Most of the patients received their diagnosis alone and were informed only by their physician. Communication was essentially focused on verbal aspects. The way the diagnosis was transmitted across the sample was not influenced by socio-demographic nor clinical variables.

According to the results of this study, the four categories related to patients' preferences for communication in cancer suggested by Fujimori also seem to be applicable in the communication of the diagnosis of HIV patients.

The majority of the items in "emotional support" consistently received high preference ratings, which happened solely in this category. In general terms, when given an HIV-infection diagnosis, patients showed little preference for being accompanied by significant others or for the presence of other health professionals beyond their physician. According to some studies, this is different from what happens in cancer communication. In our study, patient nationality and context where patients received the diagnosis influenced patients' preferences.

Agreement or tendency for agreement between the experiences patients had at the time of the diagnosis and their preferences regarding this moment were found for items with general low value for the sample. These agreements probably have little impact in the wider sense of communication with HIV patients.

There was tendency for disagreement in some aspects, such as the term

HIV/AIDS being used, discussing diseases' implications in everyday life and being given information about treatment options, meaning that these aspects happened more than patients wanted (and vice-versa). On the other hand, aspects that all patients valued highly happened at the time of the diagnosis only for some, but not for others. Most of these items pertain to the category "emotional support", which plays a key role in communicating with HIV patients. There is room for improvement when considering these two situations. This can only happen with an individualized approach to every patient, trying to understand what are the real needs of each one of them.

Communication skills in medical consultation can be taught and improved, and it is, therefore, important that those responsible for the training of staff dealing with the notification of diagnosis HIV infection are aware of their patients' views about the responses to medical communications[4]. Such efforts are important because providing unfavorable news effectively may improve patients' compliance with treatment, lead to a clearer understanding of instructions or symptoms, helps reduce stress and anxiety, and improve patient satisfaction[18].

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# APPENDIX

# Questionnaire

## I. Patients' experiences regarding communication of the diagnosis of HIV infection

Listed below are different statements related to the situation in which you might find yourself when you have received the diagnosis of HIV infection. Please indicate if it did **("yes")** or did not happened **("no")** by crossing one possibility.

| **The physician[1]:** | YES | NO |
|---|---|---|
| 1. Asked what I knew about the disease before breaking bad news | | |
| 2. Asked how much information I would like to receive | | |
| 3. Gave me information in a clear and understandable way | | |
| 4. Did not use medical/technical language | | |
| 5. Gave me the information gradually | | |
| 6. Gave me the information with the help of exams/tests/drawings | | |
| 7. Immediately transmitted all diagnosis details | | |
| 8. Gave me customized/personalized information | | |
| 9. Told me the chances of cure | | |
| 10. Discussed the disease's implications in my everyday life | | |
| 11. Greeted me before starting the appointment | | |
| 12. Gave me information without interruptions | | |
| 13. Encouraged me to ask questions | | |
| 14. Gave me extra written information | | |
| 15. Gave me information about the treatment | | |
| 16. Gave me information about the disease progression | | |
| 17. Checked to see if I understood the information | | |
| 18. The physician alone gave me the information | | |
| 19. Gave me the information with other health professionals | | |
| 20. The senior doctor gave me the information after discussing it with the team | | |
| 21. Seemed to be friendly/ empathic | | |
| 22. Showed concern for my distress/fears | | |
| 23. Gave me support for my distress/fears | | |
| 24. Stayed with me until I was able to do without their support | | |
| 25. Told me in a private setting | | |
| 26. Gave the information in person (rather than over the phone) | | |
| 27. Was sitting, and I was too | | |
| 28. Asked me if I had any doubts or questions | | |
| 29. Gave me enough time to ask all of my questions | | |
| 30. I was with my spouse/ partner | | |
| 31. I was with a family member/ friend | | |
| 32. Cared for significant others who could help me deal with the news | | |
| 33. Gave me hope | | |
| 34. Scheduled a follow-up appointment | | |
| 35. Let me participate in decisions regarding treatment options | | |
| 36. Used the word "HIV/AIDS" | | |
| 37. Asked if I would like a supportive person to be present, before giving the news | | |
| 38. Asked if I needed help getting home | | |

[1] except items 28,20, 30 & 31

## II. Patients' preferences regarding communication of the diagnosis of HIV infection

Listed below are different statements related to the situation of receiving the diagnosis of HIV infection. According to the way you would like to be informed of your diagnosis, please indicate **how important** each of these issues is to you by crossing on possibility from 1 to 5, where **1 represents "completely unimportant" and 5 "extremely**

| **I would like the physician**[1]: | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
| 1. To have asked what I knew about the disease before breaking bad news | | | | | |
| 2. To have asked how much information I would like to receive | | | | | |
| 3. To have given me information in a clear and understandable way | | | | | |
| 4. To have not used medical/technical language | | | | | |
| 5. To have given me the information gradually | | | | | |
| 6. To have given me the information with the help of exams/tests/drawings | | | | | |
| 7. To have immediately transmitted all diagnosis details | | | | | |
| 8. To have given me customized/personalized information | | | | | |
| 9. To have told me the chances of cure | | | | | |
| 10. To have discussed the disease's implications in my everyday life | | | | | |
| 11. To have greeted me before starting the appointment | | | | | |
| 12. To have given me information without interruptions | | | | | |
| 13. To have encouraged me to ask questions | | | | | |
| 14. To have given me extra written information | | | | | |
| 15. To have given me information about the treatment | | | | | |
| 16. To have given me information about the disease progression | | | | | |
| 17. To have checked to see if I understood the information | | | | | |
| 18. Alone had given me the information | | | | | |
| 19. To have given me the information with other health professionals | | | | | |
| 20.To have senior doctor had given me the info. after discussing it with the team | | | | | |
| 21. To have seemed to be friendly/ empathic | | | | | |
| 22. To have showed concern for my distress/fears | | | | | |
| 23. To have given me support for my distress/fears | | | | | |
| 24. To have stayed with me until I was able to do without their support | | | | | |
| 25. To have told me in a private setting | | | | | |
| 26. To have given the information in person (rather than over the phone) | | | | | |
| 27. To have been sitting, and me too | | | | | |
| 28. To have asked me if I had any doubts or questions | | | | | |
| 29. To have given me enough time to ask all of my questions | | | | | |
| 30. I would like to be with my spouse/ partner | | | | | |
| 31. I would like to be with a family member/ friend | | | | | |
| 32. To have cared for significant others who could help me deal with the news | | | | | |
| 33. To have given me hope | | | | | |
| 34. To have scheduled a follow-up appointment | | | | | |
| 35. To have let me participate in decisions regarding treatment options | | | | | |
| 36. To have used the word "HIV/AIDS" | | | | | |
| 37. To have asked if I would like a supportive person to be present, before giving news | | | | | |
| 38. To have asked if I needed help getting home | | | | | |

[1] except items 28,20, 30 & 31

**Table 1 -** Patients' characteristics

| **Variables** | **Total (N=80)** |
|---|---|
| **Gender** – no. of patients' (%) | |
| Female | 29 (36.3) |
| Male | 51 (63.8) |
| **Age -** years (mean, SD and range) | 42.3 (8.27); [24-61] |
| **Nationality** – no. of patients' (%) | |
| Portuguese | 75 (93.8) |
| Other | 5 (6.3) |
| **Marital Status** – no. of patients' (%) | |
| Never married | 32 (40) |
| Married/ living with partner | 23 (28.8) |
| Divorced | 19 (23.3) |
| Widowed | 6 (7.5) |
| **Education -** years (mean, SD and range) | 8.35 (4.01) [4-19] |
| **Occupation** – no. of patients' (%) | |
| Employed | 31 (38.8) |
| Unemployed | 33(41.3) |
| Retired | 16 (20) |
| **Sexual Orientation** – no. of patients' (%) | |
| Heterosexual | 58 (72.5) |
| Homosexual | 16 (20) |
| Bisexual | 5 (6.3) |
| **Monthly income -** € (mean, SD and range) | 509 (485.1) [0-2500] |
| **Time since HIV diagnosis –** months (mean, SD and range) | 91.9 (77.9) [1-276] |
| **Form of HIV transmition** – no. of patients' (%) | |
| Sexual | 63 (78.8) |
| IV drugs | 17 (21.3) |
| **Location of the diagnosis** – no. of patients' (%) | |
| Emergency room | 11 (13.8) |
| Primary Care Centre | 13 (16.3) |
| Outpatient Care (Hospital) | 13 (16.3) |
| Inpatient Care (Hospital) | 19 (23.8) |
| By letter | 6 (7.5) |
| Others | 15 (18.8) |

**Table 2** – Categories and corresponding items

"The physician":

**Setting**
11. Greeted me before starting the appointment
12. Gave me information without interruptions
18. The physician alone gave me the information
19. Gave me the information with other health professionals
20. The senior doctor gave me the information after discussing it with the team
25. Told me in a private setting
26. Gave the information in person (rather than over the phone)
27. Was sitting, and I was too
29. Gave me enough time to ask all of my questions
30. I was with my spouse/ partner
31. I was with a family member/ friend
37. Asked if I would like a supportive person to be present, before giving the news

**Manner of communicating the diagnosis**
1. Asked what I knew about the disease before breaking bad news
2. Asked how much information I would like to receive
3. Gave me information in a clear and understandable way
4. Did not use medical/technical language
5. Gave me the information gradually
8. Gave me customized/personalized information
14. Gave me extra written information
17. Checked to see if I understood the information
28. Asked me if I had any doubts or questions

**What and how much information was provided**
6. Gave me the information with the help of exams/tests/drawings
7. Immediately transmitted all diagnosis details
9. Told me the chances of cure
10. Discussed the disease's implications in my everyday life
15. Gave me information about the treatment
16. Gave me information about the disease's progression
35. Let me participate in decisions regarding treatment options
36. Used the word "HIV/AIDS

**Emotional support**
13. Encouraged me to ask questions
21. Seemed to be friendly/ empathic
22. Showed concern for my distress/fears
23. Gave me support for my distress/fears
24. Stayed with me until I was able to do without their support
32. Cared for significant others who could help me deal with the news
33. Gave me hope
34. Scheduled a follow-up appointment
38. Asked if I needed help getting home

**Table 3** – Patients' experiences regarding communication of the diagnosis of HIV infection[1] (Frequency and Percentage)

[1]Six patients received the diagnosis by letter, thus did not respond to this part of the questionnaire.

| ITEMS | YES | |
|---|---|---|
| | n | (%) |
| 36. Used the word "HIV/AIDS (W) | 69 | 93.2 |
| 27. Was sitting, and I was too (S) | 68 | 91.9 |
| 26. Gave the information in person (rather than over the phone) (S) | 66 | 89.2 |
| 3. Gave me information in a clear and understandable way (M) | 65 | 87.8 |
| 12. Gave me information without interruptions (S) | 64 | 87.7 |
| 25. Told me in a private setting (S) | 64 | 86.5 |
| 18. The physician alone gave me the information (S) | 62 | 83.8 |
| 34. Scheduled a follow-up appointment (E) | 62 | 83.8 |
| 21. Seemed to be friendly/ empathic (E) | 60 | 82.2 |
| 11. Greeted me before starting the appointment (S) | 60 | 81.1 |
| 10. Discussed the disease's implications in my everyday life (W) | 57 | 77.0 |
| 15. Gave me information about the treatment (W) | 53 | 71.6 |
| 33. Gave me hope (E) | 53 | 71.6 |
| 8. Gave me customized/personalized information (M) | 52 | 70.3 |
| 24. Stayed with me until I was able to do without their support (E) | 51 | 69.9 |
| 29. Gave me enough time to ask all of my questions (S) | 51 | 69.9 |
| 17. Checked to see if I understood the information (M) | 51 | 68.9 |
| 5. Gave me the information gradually (M) | 50 | 67.6 |
| 28. Asked me if I had any doubts or questions (M) | 50 | 67.6 |
| 4. Did not use medical/technical language (M) | 48 | 64.9 |
| 13. Encouraged me to ask questions (E) | 47 | 63.5 |
| 23. Gave me support for my distress/fears (E) | 47 | 63.5 |
| 22. Showed concern for my distress/fears (E) | 46 | 63.0 |
| 16. Gave me information about the disease's progression (W) | 46 | 62.2 |
| 7. Immediately transmitted all diagnosis details (W) | 44 | 59.5 |
| 1. Asked what I knew about the disease before breaking bad news (M) | 38 | 51.4 |
| 35. Let me participate in decisions regarding treatment options (W) | 37 | 50.0 |
| 9. Told me the chances of cure (W) | 34 | 45.9 |
| 32. Cared for significant others who could help me deal with the news (E) | 33 | 44.6 |
| 2. Asked how much information I would like to receive (M) | 32 | 43.2 |
| 20. The senior doctor gave me the information after discussing it with the team (S) | 28 | 37.8 |
| 37. Asked if I would like a supportive person to be present, before giving the news (S) | 28 | 37.8 |
| 6. Gave me the information with the help of exams/tests/drawings (W) | 27 | 36.5 |
| 14. Gave me extra written information (M) | 23 | 31.1 |
| 38. Asked if I needed help getting home (E) | 21 | 28.4 |
| 19. Gave me the information with other health professionals (S) | 21 | 28.4 |
| 31. I was with a family member/ friend (S) | 17 | 23.3 |
| 30. I was with my spouse/ partner (S) | 15 | 20.3 |

S – Setting
M – Manner of communicating the diagnosis
W – What and how much information was provided
E – Emotional support

**Table 4 -** Patients' preferences regarding the communication of the diagnosis of HIV infection (Mean and Standard Deviation)

| Items | Mean | SD |
|---|---|---|
| 3. I would like the physician to have given me information in a clear and understandable way (M) | 4.95 | 0.27 |
| 28. I would like the physician to have asked me if I had any doubts or questions (M) | 4.89 | 4.23 |
| 10. I would like the physician to have discussed the disease's implications in my everyday life (W) | 4.89 | 0.45 |
| 16. I would like the physician to have given me information about the disease's progression (W) | 4.88 | 0.46 |
| 25. I would like the physician to have (…) told me in a private setting (S) | 4.89 | 0.55 |
| 26. I would like the physician to have given the information person (rather than over the phone) (S) | 4.85 | 0.68 |
| 34. I would like the physician to have scheduled a follow-up appointment (E) | 4.85 | 0.42 |
| 17. I would like the physician to have checked to see if I understood the information (M) | 4.84 | 0.49 |
| 23. I would like the physician to have given me support for my distress/fears (E) | 4.83 | 0.52 |
| 13. I would like the physician to have encouraged me to ask questions (E) | 4.81 | 0.62 |
| 15. I would like the physician to have given me information about the treatment (W) | 4.81 | 0.55 |
| 29. I would like the physician to have given me enough time to ask all of my questions (S) | 4.79 | 0.71 |
| 21. I would like the physician to have seemed to be friendly/ empathic (E) | 4.78 | 0.60 |
| 22. I would like the physician to have showed concern for my distress/fears (E) | 4.75 | 0.65 |
| 33. I would like the physician to have given me hope (E) | 4.75 | 0.76 |
| 24.I would like (…) have stayed with me until I was able to do without their support (E) | 4.73 | 0.76 |
| 1. I would like (…) have asked what I knew about the disease before breaking bad news (M) | 4.65 | 0.89 |
| 12. I would like the physician to have given me information without interruptions (S) | 4.65 | 0.94 |
| 35. I would like (…) have let me participate in decisions regarding treatment options (W) | 4.65 | 0.93 |
| 9. I would like the physician to have told me the chances of cure (W) | 4.64 | 0.96 |
| 27. I would like the physician to have been sitting, and me too (E) | 4.63 | 0.83 |
| 18. I would like the physician to have alone to have given me the information (E) | 4.53 | 0.99 |
| 11. I would like the physician to have greeted me before starting the appointment (E) | 4.50 | 1.04 |
| 8. I would like the physician to have given me customized/personalized information (M) | 4.49 | 0.95 |
| 5. I would like the physician to have given me the information gradually (M) | 4.47 | 1.53 |
| 2. I would like the physician to have asked how much information I would like to receive (M) | 4.43 | 1.11 |
| 38. I would like the physician to have asked if I needed help getting home (E) | 4.23 | 1.29 |
| 36. I would like the physician to have used the word "HIV/AIDS" (W) | 4.20 | 1.28 |
| 37. I would (…) asked if I would like a supportive person to be present, before giving the news (E) | 4.14 | 1.39 |
| 32. I would like (…) have cared for significant others who could help me deal with the news (E) | 4.09 | 1.39 |
| 4. I would like the physician to have not used medical/technical language (M) | 4.00 | 1.53 |
| 7. I would like the physician to have immediately transmitted all diagnosis details (W) | 3.64 | 1.68 |
| 20. I would like the senior doctor have given me the info. after discussing it with the team (S) | 3.38 | 1.69 |
| 6. I would like (…) have given me the information with the help of exams/tests/drawings (W) | 3.35 | 1.70 |
| 30. I would like to be with my spouse/ partner (E) | 2.91 | 1.79 |
| 14. I would like the physician to have given me extra written information (M) | 2.88 | 1.75 |
| 19. I would like the physician to have given me the information with other health professionals (E) | 2.86 | 1.80 |
| 31. I would like to be with a family member/friend (E) | 2.65 | 1.79 |
| | Total Mean = 4.35(SD= 0.66) | |

S – Setting
M – Manner of communicating the diagnosis
W – What and how much information was provided
E – Emotional support

**Table 5** – Comparison between experiences and preferences regarding communication of the diagnosis of HIV infection.

| ITEMS | Yes[1] Mean | Yes[1] SD | No[2] Mean | No[2] SD | Y-N differ. Mean | Y-N differ. SD |
|---|---|---|---|---|---|---|
| 19. Gave me the information with other health professionals (S) | 4.48 | 0.98 | 2.25 | 1.65 | 2.23* | -0.67 |
| 30. I was with my spouse/ partner (S) | 4.47 | 1.13 | 2.49 | 1.74 | 1.98* | -0.61 |
| 31. I was with a family member/ friend (S) | 3.71 | 1.69 | 2.29 | 1.68 | 1.42 | 0.01 |
| 2. Asked how much information I would like to receive (M) | 4.50 | 0.95 | 4.45 | 1.15 | 0.05 | -0.20 |
| 6. Gave me the information with the help of exams/tests/drawings (W) | 4.00 | 1.69 | 2.98 | 1.66 | 1.02 | 0.03 |
| 20. The senior doctor gave me the information after discussing it with the team (S) | 4.04 | 1.45 | 3.13 | 1.73 | 0.91 | -0.28 |
| 18. The physician alone gave me the information (S) | 4.73 | 0.83 | 3.83 | 1.27 | 0.90 | -0.44 |
| 8. Gave me customized/personalized information (M) | 4.78 | 0.54 | 3.91 | 1.38 | 0.87 | -0.84 |
| 4. Did not use medical/technical language (M) | 4.17 | 1.37 | 3.37 | 1.82 | 0.80 | -0.45 |
| 32. Cared for significant others who could help me deal with the news (E) | 4.42 | 1.23 | 3.78 | 1.70 | 0.64 | -0.47 |
| 25. Told me in a private setting (S) | 4.97 | 0.25 | 4.40 | 1.35 | 0.57 | -1.10 |
| 7. Immediately transmitted all diagnosis details (W) | 3.82 | 1.62 | 3.47 | 1.74 | 0.35 | -0.12 |
| 9. Told me the chances of cure (W) | 4.82 | 0.52 | 4.48 | 1.24 | 0.34 | -0.72 |
| 34. Scheduled a follow-up appointment (E) | 4.90 | 0.35 | 4.58 | 0.67 | 0.32 | -0.32 |
| 37. Asked if I would like a supportive person to be present, before giving the news (S) | 4.36 | 1.31 | 4.09 | 1.44 | 0.27 | -0.13 |
| 5. Gave me the information gradually (M) | 4.59 | 1.04 | 4.38 | 1.25 | 0.21 | -0.21 |
| 28. Asked me if I had any doubts or questions (M) | 4.96 | 0.29 | 4.75 | 0.61 | 0.21 | -0.32 |
| 14. Gave me extra written information (M) | 3.13 | 1.71 | 2.94 | 1.79 | 0.19 | -0.08 |
| 17. Checked to see if I understood the information (M) | 4.92 | 0.34 | 4.74 | 0.62 | 0.18 | -0.28 |
| 11. Greeted me before starting the appointment (S) | 4.53 | 1.08 | 4.36 | 1.08 | 0.17 | 0.00 |
| 13. Encouraged me to ask questions (E) | 4.87 | 0.45 | 4.70 | 0.87 | 0.17 | -0.42 |
| 24. Stayed with me until I was able to do without their support (E) | 4.84 | 0.46 | 4.68 | 0.89 | 0.16 | -0.43 |
| 35. Let me participate in decisions regarding treatment options (W) | 4.73 | 0.93 | 4.62 | 0.95 | 0.11 | -0.02 |
| 29. Gave me enough time to ask all of my questions (S) | 4.84 | 0.64 | 4.73 | 0.88 | 0.11 | -0.24 |
| 33. Gave me hope (E) | 4.77 | 0.70 | 4.71 | 0.96 | 0.06 | -0.26 |
| 38. Asked if I needed help getting home (E) | 4.29 | 1.45 | 4.25 | 1.27 | 0.04 | 0.18 |
| 23. Gave me support for my distress/fears (E) | 4.89 | 0.43 | 4.87 | 0.58 | 0.02 | -0.15 |
| 12. Gave me information without interruptions (S) | 4.75 | 0.82 | 4.78 | 0.67 | -0.03 | 0.15 |
| 22. Showed concern for my distress/fears (E) | 4.78 | 0.63 | 4.81 | 0.40 | -0.03 | 0.23 |
| 27. Was sitting, and I was too (E) | 4.63 | 0.86 | 4.67 | 0.82 | -0.04 | 0.04 |
| 3. Gave me information in a clear and understandable way (M) | 4.95 | 0.28 | 5.00 | 0.00 | -0.05 | 0.28 |
| 16. Gave me information about the disease's progression (W) | 4.87 | 0.50 | 4.96 | 0.19 | -0.09 | 0.31 |
| 1. Asked what I knew about the disease before breaking bad news (M) | 4.74 | 0.80 | 4.58 | 1.03 | -0.11 | -0.23 |
| 21. Seemed to be friendly/ empathic (E) | 4.78 | 0.61 | 4.92 | 0.28 | -0.14 | 0.33 |
| 10. Discussed the disease's implications in my everyday life (W) | 4.86 | 0.52 | 5.00 | 0.00 | -0.14 | 0.52 |
| 26. Gave the information in person (rather than over the phone) (S) | 4.83 | 0.74 | 5.00 | 0.00 | -0.17 | 0.74 |
| 15. Gave me information about the treatment (W) | 4.79 | 0.60 | 5.00 | 0.00 | -0.21 | 0.60 |
| 36. Used the word "HIV/AIDS" (W) | 4.19 | 1.33 | 4.80 | 0.45 | -0.61 | 0.88 |

* $p \leq 0.001$ ("Yes" - Mean = 4.57 SD=0.14) ("No"- Mean =4.23 SD=0.80)

1 - **Happened** in the communication of the diagnosis of HIV infection
2 – **Did not happen** in the communication of the diagnosis of HIV infection